Shared decision making in mental health care

Metz, M.J.

2018

document version
Publisher's PDF, also known as Version of record

Shared decision making in mental health care

The added value for patients and clinicians

Summary

Summary

As has been described in **Chapter 1**, general introduction, this thesis seeks to establish the added value of shared decision making (SDM) for patients and clinicians in mental health care. It also examines the extent to which the use of Routine Outcome Monitoring (ROM) and eHealth may be helpful to patients and clinicians in shared decision making concerning treatment options. So far, little research is known in the field of mental health care on the application of shared decision making, using ROM and eHealth as integrated resources. In Dutch mental health care, annually some 700,000 patients are treated within approximately 175 mental health care organisations, varying from large, regional organisations to small clinical practices. An estimated 89,000 staff are employed in mental health care in the Netherlands.

In recent years we have seen increasing attention in mental health care for the implementation of SDM in clinical practice. SDM is a collaborative approach in which patients, in dialogue with their companions and clinicians jointly make decisions about treatment options.
This dialogue takes place on a level playing field where each person's expertise is shared, information is exchanged about treatment options and active participation by patients is supported. Research on the implementation of SDM in mental health care has shown that this approach can have a positive effect: patients are better informed, they are more actively involved in their treatment, they report higher patient satisfaction and they show greater treatment adherence. This can ultimately lead to better treatment outcomes. Despite these promising results from shared decision making, SDM is not yet widely applied in mental health care; there is considerable room for improvement in this respect. In order to bridge the gap between the promising research findings and daily practice, it is important that both clinicians and patients are supported in playing their part in this relatively new manner of collaboration. As described in **Chapter 1**, in this thesis we have examined the extent to which the use of ROM and eHealth might be useful in furthering this process.

ROM is a personalised information resource that affords patients and clinicians insight into the nature and severity of the health condition at the start of, during, and at the end of treatment. The primary objective of ROM is to provide

feedback to patients and clinicians on the progression of treatment and it can therefore also be used as a tool to assist in shared decision making about treatment options. Research has shown that using ROM feedback can improve communication between patients and clinicians, and may also have a positive effect on treatment outcomes. Especially when a patient has made insufficient progress with a chosen treatment, and the clinician uses ROM feedback, in collaboration with the patient, to make prompt adjustments to the treatment. Besides the above-stated primary objective, ROM is also used within teams for learning purposes and to improve care processes, as well as for research and for external accountability. In recent years the focus in the Netherlands has been on the use of ROM for external accountability, which has resulted in a negative image of ROM among patients and clinicians. Consequently the instrument has been little used in clinical practice, despite its demonstrated usefulness as a feedback instrument for patients and clinicians, when it is applied correctly, tailored to the information requirement of each patient group. In view of the potential of ROM, and with the aim of encouraging its use in clinical practice, the National Quality Improvement Collaborative for the clinical use of ROM (ROM Breakthrough project) was launched in 2014. Public sector mental health care teams, as well as independent practices, working with various target groups spread across the whole country, participated in the project. ROM Breakthrough has been executed by the Trimbos Institute, on behalf of the National Mental Health Care Platform, the Netherlands Psychiatric Association, the Dutch Association of Psychologists and the Dutch Association of Mental Health and Addiction Care. It was funded by the National Network for Quality Development in mental health care.

Besides ROM, eHealth may also be useful for the application of SDM. In our study, eHealth comprises an internet intervention during intake. This intervention aims to prepare patients for the intake consultations by providing information and determining their expectations, preferences and needs. This blended eHealth intervention consisted of two modules, integrated with the ROM intake, which patients complete (together with their companions). The purpose of the intervention was to enable the patients to be better prepared for participation in the intake consultations with the clinician. Although research has shown that eHealth can have a positive impact on active participation by the patient in treatment and can lead to better treatment outcomes, relatively

little research has been conducted on the application of eHealth in mental health care. Moreover, the integration of eHealth and ROM in clinical practice approach is still relatively new.

As a consequence of the increasing focus on shared decision making, the need has arisen to evaluate its application in practice. A construct that may be helpful in this respect is 'decisional conflict' (DC). This construct has been described in greater detail in **Chapter 2** and captured in a model, based on study of the literature. Decisional conflict is a multi-dimensional concept that, from the patient's perspective, affords insight into the quality of the decision making process and the decisions that have been taken. Decisional conflict is related to the nature of the collaboration between patient and clinician, and as such is a transactional concept. The dimensions of the construct are: 1) feeling informed about treatment options, 2) feeling supported in making choices and not pressured by others, 3) having clarity about one's own values, which are important for making a decision, 4) the degree of certainty in choosing the best suitable options, 5) the degree of satisfaction and commitment regarding the decisions taken. When facing a difficult decision about the treatment, it is logical that the degree of decisional conflict will be high at the start of the decision making process. If the process then concludes satisfactorily after careful deliberation, the patient will generally feel less uncertain and more comfortable about the decision, resulting in a reduction of decisional conflict. Feeling less decisional conflict is a good thing, because this has a positive influence on satisfaction with the treatment, the degree of commitment to the treatment and treatment outcomes. A high degree of decisional conflict can have negative consequences, such as delaying decision making, disappointment, dissatisfaction about the treatment, drop-out and poorer treatment outcomes. Research has shown that shared decision making can reduce the degree of decisional conflict. As has been shown, particularly from research in general health care, decisional conflict is an useful measure for evaluating the quality of clinical decision making. For research purposes and for use in practice, this concept can be measured with the decisional conflict scale. Besides having an overall score, this instrument has a number of sub-scores on the above-cited five dimensions. To date, the concept of decisional conflict has been little used in mental health care, despite the fact that it can offer added value in this sector, by improving our understanding of decision making about

treatment, and the extent to which shared decision making is applied. **Chapter 3** describes the findings of a cross-sectional study which measured the degree to which patients in specialist mental health care experience decisional conflict. The study also examined the influence of socio-demographic and clinical variables on the level of decisional conflict experienced. The findings show that patients who are treated in specialist mental health care settings typically report considerable DC on all five dimensions. Accordingly, this shows there is room for improvement in the quality of clinical decision making in specialist mental health care. In particular, patients who experience little control over the circumstances of their own life - i.e. they report less internal locus of control - score significantly higher for DC on the total scale and for all five dimensions of the DC scale. As we assumed earlier, patients with a primary diagnosis of personality disorder also experience more decisional conflict. This can be attributed to the fact that people in this group experience less locus of control. As was expected on the basis of earlier research, we found that women reported less DC on the sub domain 'information'. Patients with a primary diagnosis of psychosis also experience less DC on the sub domain 'certainty in choosing the best suitable options'. This could be explained by the longer treatment duration that these patients have, with the same clinical team. Consequently there may be a better working relationship and more participation in decision making, leading to a reduction in decisional conflict. Conversely, a longer treatment duration leading to hospitalisation could result in the patient playing a more passive role. This could make it easier for patients to accept treatment decisions, or fear that if they don't agree with the clinician, they may face compulsory treatment. Interestingly, more educated patients experience more DC on the subdomain 'clarity about one's own values'. This may be explained by the likelihood that more educated patients are better informed about the treatment options, and therefore have a better understanding of the complexity of the decision to be made. It is therefore possibly more difficult for this group to obtain clarity for themselves about which values are important to them in order to make an appropriate decision. Finally, we found no effect for age or treatment setting on the extent to which patients experienced decisional conflict.

After **Part I** of this thesis explored the concept of decisional conflict and the extent to which it is experienced, **Part II** described the results of the national ROM Breakthrough project. In this nationwide project, ROM was implemented

by the participating Breakthrough teams matched to each patient group, as a personalised information resource to be used in shared decision making. The Breakthrough teams - also known as intervention teams - executed a comprehensive improvement programme, using the Breakthrough method, consisting of national and regional implementation techniques, in which the Plan - Do - Check - Act (PDCA) cycle is central. Elements of the method include: attending conferences as well as training and booster sessions with a view to building up expertise; learning new skills and exchanging experiences; having the opportunity to consult experts on content and processes, including patient representatives; attending local multi-disciplinary team meetings to work on one's own team's improvement plans; and receiving feedback information to further the team's learning and improvement cycle. In this second part of the thesis, **Chapter 4** discusses the findings of the implementation study. This study examined the extent to which clinicians in the Breakthrough (intervention) teams, compared to the Shadow (control) teams, used ROM more effectively in daily practice and found it to be useful. The results of this study are very positive for the intervention teams. All three groups of clinicians from the intervention teams - doctors, psychologists and nurses - experienced more benefit from using ROM in clinical practice. **Chapter 5** subsequently deals with the research protocol of the national, multi-centre study, in which the effects of implementing shared decision making using ROM, were examined. In this trial, pairs of matched teams from the same mental health care organisation were randomised, according to the 'matched-paired' cluster randomised design. In the intervention teams, the 5-step model of SDM using ROM was implemented. This was executed by means of training and peer-review sessions for clinicians. The method comprised the following 5 steps: 1) introducing the choice to be made, exploring goals and expectations, discussing which role patients and their companions are able and willing to play in the decision making, 2) give meaning to ROM and other information resources, 3) exploring options from a neutral position, 4) weighing up the options, 5) making a shared decision and agreeing on the next step. According to our hypotheses, the application of shared decision making, integrated with ROM in the intervention teams would lead to reduced decisional conflict as a primary outcome; we also hypothesised that a secondary outcome would be a positive influence on the working alliance, commitment to treatment and treatment outcomes. The results of the RCT are subsequently described in **Chapter 6**. In total, 186

patients (94 intervention, 92 control), 57 clinicians (25 intervention, 32 control) and 14 teams (7 intervention, 7 control) from four organisations spread across the country participated in this study. With regard to the total patient group participating, from the patients' perspective, no difference was found between the two conditions in the primary and secondary outcome measures. However, sub-group analyses showed a significantly positive effect of the intervention, with less experienced decisional conflict in the group of patients with a primary diagnosis of depression. Although we initially thought that shared decision making in specialist mental health care could be encouraged by means of a generic intervention aimed at clinicians, it has transpired from our study that this intervention was not sufficiently effective and was too generic to stimulate SDM in the varied group of patients that are treated in these settings. In contrast to the outcome parameters scored by patients, clinicians from the intervention group reported having experienced a better working relationship and feeling more committed to the treatment decisions taken. The more positive rating by clinicians could be explained by the fact that they were supported by the national intervention in the application of SDM using ROM. Consequently they were aware of a different method of collaboration, whereas the patients still had to become accustomed to this new role and were not directly supported in this. The outcomes on the process parameters show that in the intervention group both patients and clinicians reported better use of ROM feedback in treatment, whereas the application of SDM had not yet improved in the intervention group compared to the control group. Finally, we found that when SDM and ROM were well implemented in clinical practice according to the patients, there were positive associations, with less experienced DC and better treatment outcomes. Despite the limited trial results, these associations are very encouraging for warranting further investment in the implementation of and research on shared decision making in clinical practice.

In addition to the national initiative, **Part III** describes the implementation, research approach and results of SDM in a revised intake approach at GGz Breburg. GGz Breburg is an integrated, specialist mental health care organisation in the region of Breda and Tilburg. In this approach, both patients and clinicians were directly supported in SDM during the intake phase. The support consisted of eHealth combined with ROM, input from peer workers, training, as well as clinician peer review. The results of this approach have been

evaluated in a matched-pair cluster randomised trial. **Chapter 7** discusses the research protocol of this trial, in which matched intake teams were randomised within a department. We hypothesised that, compared with the usual intake procedure, using SDM in a new approach would lead to: 1) reduced decisional conflict, 2) better application of SDM, 3) greater patient participation, 4) a better working relationship, 5) more commitment to the treatment, and 6) improved treatment outcomes. In **Chapter 8** the results of this study are described. A total of eight teams (4 intervention, 4 control), 56 pairs of intake clinicians (29 intervention, 27 control) and 200 patients (94 intervention, 106 control) participated in this study. No significant effects from the intervention were found on the primary outcome measure decisional conflict. However, the second measurement, taken two months after intake, showed a significant improvement in the application of SDM in the intervention group, as well as better treatment outcomes. There were no differences between the conditions in the other secondary outcome parameters - patient participation, working alliance, commitment to treatment and treatment outcomes. Despite the fact that the approach was aimed at both patients and clinicians, this intervention was not sufficiently effective to positively influence all outcome parameters. In view of the positive results from the intervention in the area of application of SDM and reduction of symptoms, it appears that training clinicians in SDM, with a focus on a recovery oriented approach to the treatment was the most effective element. As was the case in the national trial, we also found that a better application of SDM had a positive influence on reducing decisional conflict. This was also associated with better treatment outcomes in our study. These associations confirm the importance of making further investment in the implementation of SDM, particularly in the area of patient support, in this relatively new working method.

Chapter 9 contains the general discussion of this thesis. The findings are summarised in this chapter and are subjected to consideration from a broader perspective. There is also a discussion on the strengths and limitations of the research, and an analysis of the influence these may have had on the results. A strength of this thesis is that various research methods were used, including two cluster randomised trials on the effects of SDM. These two trials took place in daily clinical practice among a diverse group of patients, which means the external validity of the study is high, and the results can be generalised to

a broad patient group being treated in specialist mental health care. To our knowledge, these are the first randomised trials that have examined combined initiatives of this nature in the area of SDM incorporating ROM and eHealth. Both trials were conducted according to a matched-pair design, with matched randomised teams. Partly for this reason, no differences were found between the conditions, in either study, in patient or clinical characteristics, or in drop-out percentages. Another strength of both trials is the independent data collection, largely conducted with questionnaires separate from treatment and executed by independent research assistants. This method reduced the likelihood of socially desirable responses and influence by the researcher or the clinician on the outcomes. Finally, probably partly due to the stratified manner of randomisation at team level, we found no significant cluster effects at this team level. Interestingly, we did find significant cluster effects in both studies at clinician level. An obvious explanation would be that this is due to the nature of the intervention, where the attitude and skills of the clinician exert a considerable influence on the results. In fact, earlier research on SDM has shown that there is a strong association between the extent to which SDM is applied and the collaboration style, attitude and skills of clinicians. Research on the implementation of ROM shows similar associations between clinician characteristics and the use of ROM feedback in treatment. It is therefore recommended that further study be conducted on the influence of these clinician features on the application of SDM, in order to take these into consideration for future interventions.

For the correct interpretation of the trial results, it is also important to take account of a number of methodological limitations. Although our study contends that DC is a useful construct for evaluating the quality of clinical decision making, the total score on this construct is sometimes difficult to interpret. Because of the multi-dimensional nature of the construct, the scores on the subscales need not always show the same picture. For instance, the correct application of SDM may influence the scores on a number of sub-scales positively, but when a decision is difficult, uncertainty about the right choice may remain high. Moreover, we found that there is an association between patient characteristics and scores on the various dimensions of DC. We therefore recommend that in future research and in clinical practice, not only the overall concept of DC but particularly the five dimensions of the construct

should also be taken into consideration.

A limitation of both trials is that the participating clinicians could not be blinded to the condition. This is due to the nature of the intervention. It is therefore possible that clinicians from the control conditions also made an effort to improve SDM. Equally, clinicians from the control teams may have become aware of the experiences of colleagues from the intervention teams and/or have become influenced by the increasing focus in the entire mental health care field on SDM, ROM and eHealth. Accordingly, it is possible that the differences between the intervention and control conditions are in fact smaller. Likewise, we don't know to what extent clinicians and patients continued with the application of SDM using ROM and eHealth after the studies, nor do we have any knowledge of the long term effects of this approach. Furthermore, our studies provided us with a limited picture of the association between patient and clinical characteristics and the extent of experienced DC. Nor did we examine which clinician characteristics may influence SDM, while we did find a high clustering of results between clinicians on the primary outcome measure.

In a future-oriented projection of the findings, **Chapter 9** reflects on the implications of the study results for daily clinical practice and for further research.

First, we recommend that the multi-dimensional construct decisional conflict be used more often in the evaluation of clinical decision making and the application of SDM, in both clinical practice and in research. It is important to take account of the five dimensions of this construct as well as the influence of patient characteristics. Effectiveness increases when the SDM support is linked to the dimensions in which patients score highly and which could differ per patient group. In addition to DC, it is important to factor in the attitude of the patient and their companions towards shared decision making about the treatment. For this reason, **Chapter 9** contains a combined model, in which both DC and the patient's motivation for SDM are included.
After all, it is important to support patients and their companions in shared decision making, as appropriate to the role suited to them. Discussing the preferred role and the motives for this are therefore essential steps in the application of SDM.

A second recommendation, that we present in **Chapter 9**, concerns the importance of further investment in the development and implementation of resources to promote SDM. Implementation strategies derived from the Breakthrough method could be useful in this respect. This recommendation is furthermore based on the finding that patients in specialist mental health care typically experience a high level of decisional conflict, and despite the limited trial results, we found promising associations between the application of SDM, DC and treatment outcomes. Because SDM requires a different approach from both patients and clinicians, it is important to support both parties in this. Besides the inclusion of SDM in the study programme of psychiatrists, psychologists and nurses, it is also important, in view of the differences found in approach between clinicians, that clinicians can learn from one another. Future training and coaching should include more emphasis on the needs of clinicians, as it may not be entirely straightforward for some to apply SDM in clinical practice. So far, we have invested most in facilitating clinicians in the application of SDM. However, it is crucial that patients and their companions should also be supported in a manner and to the extent that is appropriate to their preferred role. This would afford them greater opportunity to become more active participants in decision making. The main possibilities would be support from peer workers, training and coaching, more manageable and readily accessible digital resources to help prepare for consultations, and the integration of eHealth and ROM in a personalised health environment.

To conclude, we also recommend further investment in research, such as more explorative research on the influence of patient and clinician characteristics on SDM. The results of such research would enable us to understand when and in which situations tailored support aimed at specific patient groups and clinicians is required, and when generic interventions are adequate. These insights should be factored in when developing new interventions in the future. Furthermore, it is important that more research be conducted on user patterns and the working mechanisms of eHealth, in order to gain a better understanding of when, how and for whom eHealth works and how eHealth can be used to further develop SDM. If more personalised interventions are implemented in the future, it would be useful to study the effects of these, both via qualitative research and via rigorous randomised designs with multiple intervention conditions. Likewise, the long term effects and the cost-effectiveness of shared decision making warrant further study.